

DOCUMENT RESUME

ED 397 570

EC 304 898

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 TITLE In the Line of Fire: Children with Serious Emotional Disturbance and the 104th Congress.
 INSTITUTION Bazelon Center for Mental Health Law, Washington, DC.
 PUB DATE 15 Jul 96
 NOTE 34p.
 AVAILABLE FROM Bazelon Center for Mental Health Law, 1101 Fifteenth Street, N.W., Suite 1212, Washington, DC 20005-5002.
 PUB TYPE Reports - Evaluative/Feasibility (142) -- Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

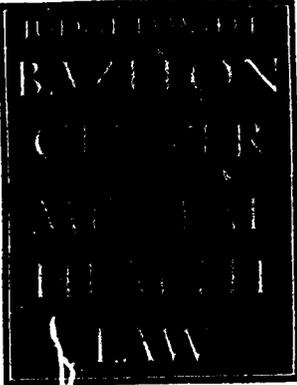
EDRS PRICE MF01/PC02 Plus Postage.
 DESCRIPTORS Adolescents; Block Grants; Budgeting; Children; Child Welfare; *Emotional Disturbances; *Federal Aid; Federal Government; Federal Legislation; *Federal Programs; Government Role; *Mental Health Programs; Policy Formation; *Public Policy; Retrenchment; Social Services; Substance Abuse; Trend Analysis

IDENTIFIERS *Child and Adolescent Service System Program; Congress 104th; Reauthorization Legislation; Substance Abuse and Mental Health Services Admin; Supplemental Security Income Program

ABSTRACT

This report summarizes and analyzes the actions of the 104th Congress in legislative areas of importance to children with serious emotional disturbances. Emphasis is on the obstacles now facing advocates and policymakers concerned with these children. An executive summary identifies program changes in child mental health services programs, Medicaid, children's Supplementary Security Income (SSI), child welfare, education, and mental health parity. The body of the report begins with a discussion of the future of CASSP (Child & Adolescent Service System Program) and other child mental health programs. It discusses the reauthorization and appropriations for the Substance Abuse and Mental Health Services Administration programs, noting implications, especially for fiscal year 1997, of the block grant approach and the decreasing commitment of the federal government to mental health services. A section on entitlement programs compares alternatives proposed by President Clinton, Congressional Republicans, the National Governors' Association, the House Coalition (conservative democrats) and the Senate Centrist Coalition (bipartisan moderates). The following sections address proposed or implemented changes and their implications in the children's SSI program, child welfare, education, and mental health parity. A concluding section offers examples of the combined impact of the proposed changes, to illustrate how difficult the situation could become for children with emotional disturbances, while noting that the inability of the Congress to enact most of these plans has temporarily preserved essential services. (DB)

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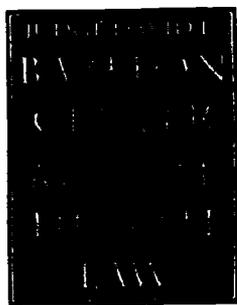
**CHILDREN WITH SERIOUS EMOTIONAL DISTURBANCE
AND THE 104TH CONGRESS**

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June 1996, updated July 15, 1996

EC304898



IN THE LINE OF FIRE

Children with Serious Emotional Disturbance and the 104th Congress

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IN THE LINE OF FIRE

Children with Serious Emotional Disturbance and the 104th Congress

INTRODUCTION

Advocates for children's mental health should take note: Congress and the public have yet to be convinced that children with mental disorders are not "just bad kids" and that their families are not "dysfunctional" and therefore part of the problem rather than part of the solution.

In November 1994, several factors combined to produce a major change in the U.S. Congress. Voters strongly supported candidates who championed a smaller role for government in general, a far less significant role for the federal government in particular and greater state responsibility for decision-making on many human services programs. While there are indications that the 104th Congress over-reacted to this shift in public opinion, it is also clear that the shift was real and that the trend in the near future will be toward less government, reduced federal expenditures and fewer federal categorical programs.

Programs for the poor make up only 25% of federal spending, but these were the ones the 104th Congress targeted for cuts. Some programs for middle-income Americans did not escape, including Medicare (where reductions were relatively modest, aimed primarily at providers) and special education. However, half the cuts—amounting to hundreds of billions of dollars—were proposed in low-income entitlements such as Medicaid, welfare, Supplemental Security Income, housing, the earned income tax credit and a host of smaller programs.

Such dramatic spending cutbacks were not possible under the laws as written, so major revisions to the underlying statutes were necessary to accomplish the goal of drastically reducing spending on these activities. And it was in the details—the proposed amendments to specific federal programs—that the animus towards children with serious emotional disturbance appeared.

Advocates for children's mental health should take note: Congress and the public have yet to be convinced that children

with mental disorders are not "just bad kids" and that their families are not "dysfunctional" and therefore part of the problem rather than part of the solution. The case has not yet been made that:

- children with serious emotional disturbance have real problems that have a real impact on their ability to function;
- families of children with mental health problems deserve support and assistance; and
- all mental disorders are amenable to treatment, and mental health services and supports are effective.

This report summarizes and analyzes the actions of the 104th Congress in a number of legislative areas of importance to children with serious emotional disturbance. Although many of these proposals have not become law, and few are expected to be enacted before Congress adjourns in October, they reflect very clearly the obstacles facing advocates and policymakers concerned about children with serious emotional disturbance.

EXECUTIVE SUMMARY OF PROGRAM CHANGES

Child Mental Health Services Programs

Programs funded through the Center for Mental Health Services may be reauthorized this year, with some changes that could reduce the priority for children. Congress also continues to scrutinize funding for all domestic programs; further cuts in child mental health services may occur in FY 1997.

Medicaid

Drastic changes proposed for Medicaid—to replace the current entitlement program with a block grant to states and to dramatically cut funding—have stalled. Although a new plan was proposed in Congress, it has now been shelved. As a result, Medicaid amendments are not likely before 1997 at the earliest. However, the consensus over the need to cap federal Medicaid funding and to give states significantly more flexibility in running their programs suggests that changes will eventually be made.

Children's SSI

The current bill, part of welfare reform, would substantially reduce SSI eligibility for children by eliminating the Individualized Functional Assessment. The rationale is that too many children with mental impairments have qualified for benefits to which they are not entitled. Congress is now moving the welfare reform bill on a fast track and these cutbacks in children's SSI could well be in place by the end of the year.

Child Welfare

Proposals to block grant many child welfare programs, including family preservation, are also linked to welfare reform (see above). The President has proposed that child welfare programs remain as under current law.

Education

Battles are raging in Congress over the degree to which schools should be allowed to suspend and otherwise discipline children with disabilities. Amendments in bills to renew the Individuals with Disabilities Education Act threaten protections that now help children with behavioral problems stay in school and continue to receive an education. IDEA renewal is on a fast track; Congress hopes to pass it before October.

Mental Health Parity

As part of its health insurance reform bill, the Senate passed an amendment requiring all health insurance plans to provide coverage for mental health services without treatment limits or cost-sharing requirements different from those imposed on other health services. A House-Senate conference is expected to create a commission to report back in 18 months. The bill may also prohibit lifetime caps or annual limits to a plan's mental health expenditures. However, because of a dispute over medical savings accounts, the health insurance bill itself is unlikely to become law.

ACTION BY THE 104TH CONGRESS ON LAWS AFFECTING CHILDREN WITH SERIOUS EMOTIONAL DISTURBANCE

The Future of CASSP and Other Child Mental Health Programs

Reauthorization of the Substance Abuse and Mental Health Services Administration programs (S 1028, S. Report 104-193) and SAMHSA appropriations bill for FY 1996 (Public Law 104-131) and FY 1997 (HR 3755).

Although the Substance Abuse and Mental Health Services Administration (SAMHSA) is permanently established in law, all of its programs, including all those in the Center for Mental Health Services, must be reauthorized periodically and are funded yearly through the appropriations process.

Reauthorization

On December 19, 1995, the Senate Labor and Human Resources Committee reported out a bill to reauthorize all of the programs of SAMHSA. Major changes that will effect children's programs include:

1 The Child Mental Health Services Program, which currently funds 22 sites providing interagency systems of care for children with serious emotional disturbance, is re-authorized essentially without change through fiscal year 1999. Funding remains stable at \$60 million in the first year.

2 All federal mental health demonstration projects, including CASSP itself and family network grants, are consolidated into a new grant program for funding priority mental health needs of regional and national significance. All future demonstration projects for adults and children will have to meet new legislative requirements and many existing projects may have to be phased out as a result. The new legislative language specifically states that "priority mental health needs of regional and national

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significance shall include child mental health services." No other area is given this priority status in the legislation. Grants under the new demonstration authority may not exceed five years (subject to appropriations being made available) and each will be evaluated following its conclusion.

3 The mental health block grant is reauthorized, but changed into a "performance partnership grant" to states to promote access to comprehensive community mental health services and to increase the development of systems of care for adults and children. For children, the bill requires that such integrated systems of care ensure the provision, in a collaborative manner, of mental health, substance abuse, education and special education, juvenile justice and child welfare services.

The federal government would establish a list of objectives for the Performance Partnership Grants, with a core set of five that address issues of national significance. To develop this list, the federal government must consult with states and other stakeholders including families. States would then develop a list of their own objectives, derived from this federal list, at least one of which must relate to children. This bill would repeal the current requirement that states set aside funds for children's services and replace it with the requirement that every state have at least one objective in its performance partnership grant with respect to children's services. A set-aside would continue to be authorized for the Center for Mental Health Services (CMHS) to provide technical assistance to the field.

The performance partnership grant program is authorized at a level of \$280 million in the first year and such sums as are necessary through fiscal year 1999.

The reauthorization bill has not yet been approved by the full Senate because of a controversy over the unrelated issue of funding religious organizations. In the House, the Commerce Committee has not held hearings on SAMHSA renewal. It is therefore quite doubtful that this bill will become law. Either the legislation will not be approved until the end of the congressional session or it will be postponed into next year. While technically the SAMHSA programs can operate for another

year if Congress appropriates the funds, leaving them unauthorized will raise questions in the next session about their value. It is preferable for the reauthorization to be enacted this year.

Implications

In general, the changes to the block grant and federal demonstration programs weaken the federal government's commitment to mental health services, especially when coupled with cuts in funding described below. However, it is important to note that the performance partnership grants emphasize children's needs and that children are the only specific mandate under the new consolidated federal demonstration program. In addition, Congress has once again reiterated its strong support for the children's mental health services program by continuing it without change and at current levels of funding.

Congress continues to single out children for special emphasis and priority within federal mental health programs. The biggest impact on child mental health programs in the next few years will not be changes in the authorizing bill, but budget cuts that accompany them. Priorities established through the authorizing legislation will not be meaningful if Congress drastically reduces funding for mental health services.

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Appropriations

The FY 1996 appropriation process was delayed considerably by the budget disagreements between the Republican-led Congress and the President. After months of delay, federal spending for FY 1996 was finalized in April, more than six months into the fiscal year.

The FY 1996 appropriation continued strong congressional support for the child mental health services program, which received \$60 million (the same as FY 1995) to continue to fund 22 interagency systems of care around the country. Other federal children's initiatives, such as grants to support family network organizations and funding for states to develop improved children's services, did not fare so well. Child and adult

mental health demonstration programs were merged and the spending for this combined program was significantly reduced from the previous year's levels to \$38.1 million.

The House of Representatives approved the FY 1997 appropriations bill, HR 3755, on July 12, funding mental health programs at approximately the same levels as last year. Specifically, both the child mental health services program and the consolidated demonstrations were level funded at \$60 million and \$38.1 million respectively.

The following chart illustrates the funding for mental health programs affecting children for fiscal years 1995 through 1997 (\$ in millions).

Program	FY 1995 Actual Spending	FY 1996 Appropriation	FY 1997 President's Request	FY 1997 House Committee
Child Mental Health Services Program	\$60.0	\$60.0	\$59.9	\$59.9
CASSP	\$12.2	*	*	*
Consolidated Demonstration for Knowledge Development and Application	\$46	\$38.1	\$62.1	\$38.1
State Block Grant	\$275	\$275	\$275	\$295.4**

* Funds for children's demonstration programs will be included in the consolidated demonstration from FY 1996 on.

**Includes funds for PATH homeless programs.

Implications

The impact of the FY 1996 and 1997 appropriations will not be as devastating for children's mental health programs as earlier appeared likely. The child mental health services program has survived intact, although it will not be able to expand to new sites as originally planned. The Center for Mental Health Services (CMHS) will continue to have the resources for research and technical assistance activities. The consolidated demonstration program, while significantly reduced, includes sufficient resources to continue to fund child mental health demonstration projects. CMHS also plans to protect some activities, including the family network grants, through other authorities such as the block grant set-aside.

ENTITLEMENT PROGRAMS

In December 1995, Congress sent President Clinton the Seven-Year Balanced Budget Reconciliation Act of 1995 (HR 2491), which he then vetoed. Since then, Congress and the President have been arguing over how to balance the federal budget and which programs to cut. Programs at risk that have a major impact on children with serious emotional disturbance are Medicaid, Supplemental Security Income (SSI) and child welfare.

Following the veto, President Clinton released his own alternative proposals to amend these programs. Although negotiations continued for some weeks, talks eventually broke off without agreement. Hoping to jump-start the talks, in early February the National Governors' Association (NGA) released an outline of its bipartisan agreement for Medicaid, Aid to Families with Dependent Children, child welfare and SSI changes.

Other significant alternatives were also proposed by a group of conservative Democrats in the House and a bipartisan moderate group in the Senate. The House Coalition is led by Representatives Bill Orton (D-UT), Charles Stenholm (D-TX), L. F. Payne (D-VA), John Tanner (D-TN), Blanche Lambert Lincoln (D-AR) and Bud Cramer (D-AL). The Senate group, known as the Centrist Coalition, consists of 22 Senators from both parties, led by John Chafee (R-RI) and John Breaux (D-LA).

After failing to achieve its goal of passing a balanced budget bill in FY 1996, Congress began the process for FY 1997. The FY 1997 budget resolution (an overall blueprint for program changes, which the President does not have to sign) aims for a balanced budget in six (not seven) years and includes significant cuts in Medicaid, SSI and welfare programs. The budget resolution sets the congressional objectives for budget cuts, but to implement them legislation must be passed to reconcile the law with the budget (this is called the reconciliation process).

Both House and Senate committees have approved their versions of a budget reconciliation bill to amend Medicaid and

Alternatives proposed by:

- ◆ *President Clinton*
 - ◆ *Congressional
Republicans*
 - ◆ *National Governors
Association (NGA)*
 - ◆ *House Coalition
(conservative Democrats)*
 - ◆ *Senate Centrist
Coalition
(bipartisan moderates)*
-

welfare programs (including SSI and child welfare). The next stage is floor action, expected in July. However, Republican leaders recently announced their decision to drop the idea of including Medicaid in this bill. As a result, only welfare reform is expected to be approved by both House and Senate; it will then be sent to a conference committee.

In the following sections, the details of the proposals from various factions are discussed by topic—Medicaid, children's SSI and child welfare. Even though the Medicaid provisions are very unlikely to be enacted, they are still relevant because the debate is likely to continue into next year.

Medicaid

Seven-Year Balanced Budget Reconciliation Act of 1995 (HR 2491, House Report 104-350), vetoed by President Clinton; Congressional Budget Resolution of FY 1997 (H Con Res 178) and Personal Responsibility and Work Opportunity Act of 1996 (HR 3507, approved by committee on June 13, and S 1795, approved by committee on June 26).

The FY 1997 congressional budget resolution assumes enactment of legislation making Medicaid a federal block grant to states and replacing the policy of individual entitlement. The new program includes cuts of \$71 billion in federal Medicaid spending. Though the recent proposal has some concessions to the Democrats, legislation approved by the House Commerce Committee and Senate Finance Committee is still very similar to the proposal vetoed by the President in 1995.

While the latest congressional proposals cut approximately \$71 billion in federal spending, total cuts in Medicaid could be as high as \$245 billion over six years if states reduce their own spending as permitted under the bills. Such a cut would reduce overall Medicaid spending *below* the amount needed to keep up with general inflation.

The new congressional plans present major problems for children with serious emotional disturbance because:

- Both House and Senate bills eliminate the direct connection between SSI benefits and Medicaid coverage by allowing states to develop their own definitions of disability. Chil-

The new congressional plan presents major problems for children with serious emotional disturbance.

dren with mental disorders are likely to be significantly disadvantaged in such a system, due to misperceptions about serious emotional disturbance.

- The House measure repeals the current-law requirement that states provide services in sufficient amount, duration and scope to meet the individual's treatment needs. This would allow and encourage states to impose arbitrary limits on treatment. The Senate measure, S 1795, restores the current guideline of requiring the amount, duration and scope of Medicaid services to "reasonably achieve its purpose." However, in the context of a block grant, this language has less meaning than under current law because states could cease to provide even medically necessary services once their federal block grant dollars are spent.
- HR 3507 weakens the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate by eliminating the "T"—the requirement that states provide any necessary service authorized under federal Medicaid law to treat a condition found as a result of an EPSDT screen. In many states this program has led to coverage of comprehensive community services for children with serious emotional disturbance. Under the House version of the Republican plan, states would have to provide only the services covered under the state's regular Medicaid plan. Once again, S 1795 has stronger language maintaining the same benefits as currently offered under the EPSDT program.
- The House Commerce Committee's plan lets states make Medicaid recipients pay a "nominal" co-payment or deductible. The current law defines nominal in relation to the "ability to pay," while the House bill defines it as a percentage of the cost of the service. Considering the rising costs of medical services, this could mean an unaffordable charge. The Finance Committee kept the current cost-sharing law, which sets limits for guaranteed populations.
- Both the House and Senate propose to deny individuals the right to bring suit in federal court if a state denies benefits. Instead, they must exhaust administrative procedures at the

Under the President's plan no change is made in current law with respect to covered services and all currently eligible population groups would remain eligible.

state level, followed by a review in state court. Individuals could not appeal to federal district court, as they can today.

- Both House and Senate bills change the requirements for state matching to allow states that now must contribute 50% of Medicaid costs to reduce that commitment to 40%. Since the new program would operate through a guaranteed payment to states (and not through a system where states can collect federal money only when they spend state resources), states would have every incentive to spend less on Medicaid services. This is why the total impact of the congressional Republicans' plans could be cuts as high as \$245 billion over six years.

The congressional plans also adapt a recommendation from the National Governors Association and establish an "umbrella" fund available to states that have unanticipated growth in the size of the covered population. However, this is not an automatic increase for any state and covers the unanticipated growth for only one year. The congressional proposals are still basically block grants, with 97% of federal funding disbursed through the block grant and only 3% available for the umbrella fund.

In contrast to the congressional proposals, the President's plan would retain current law, but cap federal expenditures to save \$54 billion over seven years. Current state matching requirements would remain in effect.

The President's plan also retains the current entitlement to health care coverage under Medicaid. Savings are achieved by placing a per capita cap on federal spending per Medicaid beneficiary (with different rates for different eligibility groups, such as low-income children or individuals with disabilities). The President also would continue current law with respect to the right to bring suit in federal court.

Under the President's plan no change is made in current law with respect to covered services and all currently eligible population groups would remain eligible.

Both House and Senate bills eliminate the requirement for states to obtain federal waivers for managed care plans or for home- and community-based services for individuals with de-

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velopmental disabilities. The President also gives states the flexibility to move to managed care (but anticipates federal standards for managed care) and permits community-based services without applying for a waiver.

Like the President's proposal, the Senate Centrist Coalition plan retains most of the current law's critical provisions. This plan would distribute funds to states under a formula that provides a guaranteed base amount plus an amount for growth in caseload and inflation. It also retains the current state-match requirements. The Centrist Coalition plan would result in Medicaid cuts of \$62 billion over seven years.

The Centrists' plan would retain all current mandatory and optional benefits, including all mental health benefits. Current eligibility mandates would also be the same, except that children who qualify for Medicaid through their SSI eligibility would have to meet the stricter definition that may pass as part of welfare reform. Consequently, children who qualified for SSI through an Individualized Functional Assessment would no longer be eligible for Medicaid unless they keep SSI eligibility through the new definition of childhood disability (see SSI section below). All other SSI-eligible individuals would, however, continue to have access to Medicaid as under current law.

The Centrists' plan also gives states flexibility with respect to home- and community-based care and managed care, but plans must meet the state's standards developed for private plans.

The plan from the House Coalition is very similar to that of the Senate moderates, although it anticipates greater savings: \$70 billion over seven years.

The chart on the next page compares the major plans' impact on children with serious emotional disturbance.

Also included in the Senate Finance Committee's bill is a provision for mental health parity. S 1795 stipulates that state Medicaid programs cannot include financial or treatment limits on mental illness services that are not also imposed on the services provided for other illnesses. That is, the amount, duration and scope of treatment must be equal for both mental and physical ailments. The parity language allows states to

Issue	HR 2491 (Vetoed)	Clinton	NGA	House Coalition	Senate Centrists	HR 3507	S 1795
Retains Title XIX	X	✓	X	✓	✓	X	X
Federal Definition of Disability	X	✓	X	✓	✓	X	X
Amount, Duration and Scope Required	X	✓	X	✓	✓	X	✓
EPSDT Treatment Mandate	X	✓	X	Allows HHS to Define	Allows HHS to Define	X	✓
Right of Action	X	✓	X	✓	✓	X	X
State Match Changed	n.a.	✓	X	✓	✓	X	X
Federal Cuts	-\$133 b	-\$54 b	None	-\$70 b	-\$62 b	-\$71 b	est. -\$71 b

✓ = acceptable

X = unacceptable

continue to use managed care to control utilization of mental health services. See page 24 for a summary of the private insurance parity bill.

Implications

Medicaid provides access to critical health care for uninsured children and now covers 18 million children in America, many of whom need mental health services. In recent years states have greatly expanded the coverage of various wrap-around community services for children with serious emotional disturbance. Medicaid's important role as a safety net for these children would be jeopardized by many of the proposals now under consideration in Washington.

Although no action is expected this year, there is considerable agreement among federal policymakers that changes must be made to Medicaid—that federal funding must be capped and that states should have greater flexibility to run their Medicaid programs. This consensus suggests that Medicaid reform will resurface in the next Congress, regardless of the outcome of the fall elections. However, as the chart above shows, what might

emerge in a 1997 Medicaid reform package will vary considerably depending upon the outcome of the presidential and congressional elections.

Children's supplemental security income (SSI) Program

Personal Responsibility Act (HR 4) passed Congress twice—once as part of the Budget Reconciliation Act, HR 2491, vetoed by President Clinton, and once as a free-standing bill, which was also vetoed. In 1996, Welfare and Medicaid Reform Act of 1996 (HR 3734 and House Report 104-651) and Personal Responsibility and Work Opportunity Act of 1996 (S 1795).

The future of the children's SSI program is part of the larger debate about welfare reform, which itself is part of the push to achieve a balanced budget over the next six or seven years. The battle over SSI began last year when the House held hearings on the program following press allegations of abuse, particularly by families of children with mental impairments. Word that SSI checks were known as "crazy checks" in some parts of the country caused Congress to seek drastic change.

Early in 1995, the House approved HR 4, a bill that would have radically restructured SSI. HR 4 would have terminated eligibility for 25% of current SSI children almost immediately and replaced cash assistance with a block grant to the states to provide services for the vast majority of children who became eligible in the future.

HR 4 proposed terminating benefits for children who qualify through an individualized functional assessment (IFA). Elimination of the IFA would overturn the 1990 U.S. Supreme Court decision in *Sullivan v. Zebley*, which required the Social Security Administration to establish a functional standard of eligibility for children "comparable" to its standard for adult applicants. Without the IFA, children would again be evaluated solely on the very restrictive "medical listings" without regard to the functional impact of their disabilities. As a result of this change, certain children with serious disabilities would not qualify for SSI benefits, including:

- those whose condition is not quite severe enough to meet the high standard of the medical listings;

Word that SSI checks were known as "crazy checks" in some parts of the country caused Congress to seek drastic change.

- those with more than one impairment if each condition by itself is not enough to qualify through the listings;
- those who are too young to test for the listings; and
- those who have rare disorders not included in any listing.

In addition to dropping hundreds of thousands of children from the rolls, the House bill also would have eliminated cash benefits for many others. Only children who are currently eligible and who met the medical listings standard, plus new applicants whose conditions resulted in their otherwise needing institutional care, would have received a cash payment. For all other children, a new—and significantly underfunded—state block grant was established to furnish services in lieu of cash payments. Which services would be available, to whom and for how long was at state discretion. The only federal guidance would be a list of services, defined by the Social Security Administration, from which states could select what services they would provide.

Fortunately, the Senate took a different approach and preserved the cash benefit program for all eligible children, although it also tightened eligibility requirements by eliminating the IFA and creating a new definition of disability. In doing so, however, the Senate bill allowed a longer time period than did the House before children would lose their current benefits. Under the Senate bill, children would be reviewed by Social Security to determine whether they were eligible under the more restrictive medical listings before being removed from the program. In contrast, under the House bill, families would have faced the burden of having to re-apply to determine if their child was eligible under the medical listings.

When the House and Senate met to negotiate their differences, they agreed to keep the cash program with a very significant and detrimental change. The bill sent to the President at the end of 1995 created a new payment scale with two types of benefits. Under this system, a child would have two evaluations: one to determine if the child is medically eligible for SSI and a second to establish the size of the child's payment. The two-tiered benefit system favored children with physical disabilities. Under the proposal, children with serious emo-

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The recent proposals have many similarities. They all use a new definition for childhood disability, eliminate the IFA and mandate continuing disability reviews every three years for all children except those whose conditions are not expected to improve.

tional disturbance would have to be in need of either 24-hour-a-day supervision or institutionalization to qualify for the full cash payment. This was essentially the same standard used by the original House proposal to deny cash assistance to most children.

Under the conference agreement, almost one million children with serious disabilities would have been denied access to SSI or have received significantly reduced benefits over the next five years. Fortunately, the President vetoed this version of welfare reform.

Other proposals on welfare reform have also included SSI changes. The NGA plan included the Senate children's SSI provisions with a later date for the changes to take effect and rejected the two-tiered benefit approach in HR. 4. Both the Senate Centrist Coalition and the House Coalition also supported the original Senate children's SSI provisions.

The most recent welfare reform proposals, (HR 3507/S 1795) are also based on the Senate bill. However, the two-tiered benefit scale has been dropped. The latest congressional plans achieve savings by adopting a new definition for childhood disability and eliminating the IFA. Children who now qualify through the IFA will be re-evaluated to determine if they are eligible through the more restrictive medical listings. If they do not re-qualify, they will lose their benefits immediately.

To highlight their new proposal, the House Human Resources Subcommittee of the House Ways and Means Committee held hearings on welfare reform in late May. Testifying in support of the children's SSI program was Kim Bell from Utah, with Shelah, her 12-year-old daughter, who qualifies for benefits through the IFA. The Bell family is highlighted in a Bazelon Center publication, *SSI: Lifeline for Children with Disabilities*. Mrs. Bell was a very powerful witness who eloquently described how the cash assistance enables their family to stay together. However, the House committee did not address her concerns.

Both HR 3507 and S 1795 have been approved in Committee and, as of July 12, were awaiting floor action. Proposals to overhaul the welfare and Medicaid programs had previously

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been combined in the same bill. However, in mid-July, congressional leaders decided to separate these issues and take up the welfare part first because it has greater bipartisan support. After the House and Senate vote, the two houses will have to resolve differences to send the President a single welfare bill for signature. The House Republican leadership has expressed hopes that Congress will pass its welfare bill before the early August recess.

If Congress approves a welfare bill, the President still has the option to veto it. That decision will depend on provisions of the final bill.

Implications

The proposed change with the greatest implication for children with serious emotional disturbance is elimination of the IFA. Among the children who now qualify through the functional assessment, 44% have mental illness or a serious emotional disorder. By losing access to cash benefits, some of these families will simply not have the resources to raise children with serious emotional disturbance at home and will turn to state and local governments for assistance. Without the federal benefits that parents now spend on behalf of their children, states' costs to serve children with serious emotional problems would inevitably increase. As an especially tragic consequence, some families may be forced to surrender custody to guarantee proper care for their children either through the foster care system or in state institutions—at enormous cost to taxpayers.

Child Welfare

Personal Responsibility Act (HR 4) passed Congress twice—once as part of the Budget Reconciliation Act, HR 2491, vetoed by President Clinton, and once as a free-standing bill, which was also vetoed. In 1996, Welfare and Medicaid Reform Act of 1996 (HR 3734, House Report 104-651) and Personal Responsibility and Work Opportunity Act of 1996 (S 1795).

The future of child welfare programs is also part of the larger debate about welfare reform. As part of the Personal Responsibility Act, the House approved the

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repeal of foster care and adoption assistance programs together with more than a dozen other child protection programs. It replaced these programs with a new block grant with significantly less funding than previously provided through the individual programs. The child welfare block grant would have been very harmful for children, including children with serious emotional disturbance, not only because it reduced funding but also because there would be no enforceable federal protections for children.

The Senate, however, rejected the House block grant and restored key child protection programs. Following a House-Senate conference, the legislation that was finally sent to the President (but vetoed) kept only part of the federal guarantee for foster care and adoption assistance. Room-and-board payments and adoption subsidies for children who cannot live safely at home were retained. However, child placement, training activities and about a dozen other child protection programs were included in two new block grants. Among the programs repealed and placed in a block grant were: foster care and adoption assistance, child placement and training, independent living, family preservation and support services and temporary child care for children with disabilities.

In its proposal, the NGA also recommended a block grant for most federal child protection programs. Further, the NGA plan gave states the option to block grant federal funds now guaranteed for foster care. In order to receive their funds in a block grant, states would have to accept a cap on the funds, but then could use them for any of a range of child protective activities. Child advocates were concerned, however, that in states that opted for the block grant, there would then be no guarantee that eligible children who could not live safely at home would be placed in foster care, as they would have been under current law.

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As Congress considers major changes in virtually all the public assistance programs for low-income families, more children and families are likely to be at risk and need help from child protection agencies. This is clearly not the time to reduce the assurance of federal support for children who cannot live safely at home.

tance. The message was also heard by the House Coalition and Senate centrists and neither of their proposals contain child protection amendments.

The new Republican welfare reform bills (HR 3734 and S 1795) also address child welfare. While the House bill would continue federal reimbursement to states for costs involved in placing and maintaining each eligible low-income child in foster care or adoption, it would consolidate existing child abuse prevention and treatment programs into a block grant. The Senate Finance Committee bill rejects the block grant approach and retains current law for all child protection programs.

Implications

The proposed child welfare block grant in HR 3734 would eliminate the recently enacted Family Preservation Act and other initiatives to enhance family support and strengthen families' abilities to keep their children safe. In implementation, prevention initiatives would likely lose out to demands for crisis services. Sadly, child abuse and neglect reports and foster care caseloads continue to increase and caseloads are expected to grow even more as families and states struggle to accommodate other proposed cutbacks in AFDC, emergency assistance, SSI and Medicaid.

As Congress considers major changes in virtually all the public assistance programs for low-income families, more children and families are likely to be at risk and need help from child protection agencies. This is clearly not the time to reduce the assurance of federal support for children who cannot live safely at home. Their very safety would be prejudiced by the combination of funding cuts, removing any assurance of increased funds as the demand increases for foster care and adoption, and the elimination of federal accountability for the care of abused and neglected children.

The child protection changes proposed in the House bill would also have significant consequences for children with serious emotional disturbance. The proposed changes in the children's SSI program would make it more difficult for parents to care for their children with disabilities at home and jeopard-

ize SSI payments for some children with disabilities who are in foster care. The loss of the current guarantee to help children who cannot remain safely with their parents could threaten federal assistance for certain eligible children in foster family homes or group homes as well as adoption subsidies for eligible children with disabilities who cannot be adopted without assistance. Children with serious emotional disturbance would also be harmed by the loss of the Family Preservation and Support Services Program and Independent Living Program, which help ensure that children do not enter or remain in care unnecessarily. These programs now help guarantee specific funds for services to keep children safely at home and to help children in care return home, move to adoptive families or, in the case of older teens, live independently.

Education

Individuals with Disabilities Education Act Amendments of 1996 (S 1578), reported by Senate Labor and Human Resources (Senate Report 104-275); IDEA Improvement Act of 1996 (HR 3268, House Report 104-614), passed by House of Representatives on June 10, 1996.

Congress is now in the process of reauthorizing the Individuals with Disabilities Education Act (IDEA). IDEA guarantees children with disabilities a free and appropriate public education. Although the basic law is permanent, the various discretionary grant programs, including a small program targeted specifically to children with serious emotional disturbance, have to be re-authorized from time to time. When this occurs, Congress also has the opportunity to review and revise the basic IDEA statute.

Claiming concerns about "school safety," Congress is considering legislation which would reverse historic protections that have dramatically improved access for children with disabilities by guaranteeing all students a "free and appropriate public education." Schools would have more authority to suspend, expel or change the placement of students with disabilities. Some students—especially those with serious emotional

Despite evidence that students with disabilities are suspended and expelled at twice the rate for the same offenses as their non-disabled peers, significant changes are proposed for the discipline section of the law.

disturbance—would likely be removed from classrooms for inappropriate reasons and some would lose all educational services. The proposals are extremely problematic for children with serious emotional disturbance, who already have the highest school dropout rate, the lowest grades and the highest failure rate among students with disabilities.

In the Senate, the Labor and Human Resources Committee unanimously approved a bill in April sponsored by Senators Bill Frist (R-TN) and Tom Harkin (D-IA) to reauthorize IDEA. However, the bill has not been scheduled for a vote yet. The House bill was passed by the full House on June 10.

Both the House and Senate bills reauthorize the discretionary programs, but consolidate them into a smaller number of new programs. The program for children with serious emotional disturbance would be permissible under both bills, but there is no explicit authority for it to continue as it now exists.

Both bills would allow schools to change the placement of students found with weapons or illegal drugs. This expands current law, which only allows schools to remove children with disabilities to an alternative placement for up to 45 calendar days if they bring guns to school. In addition, if the school expels nondisabled students who are found with weapons or drugs, both bills permit them to cease all educational services for students with disabilities who engage in these offenses if their misconduct is unrelated to their disability.

Under both bills, when students with disabilities face long-term disciplinary actions, the school would decide if the student's behavior is related to the disability through a procedure called a "manifestation determination." In some instances, students with disabilities would be protected to some degree from school discipline rules if the behavior was related to the disability. In other cases, they would not. The manifestation determination would be made by the student's IEP team. Each bill has its own list of factors to consider during the manifestation determination. For example, the Senate bill has the IEP team deciding if the disability impaired either the student's ability to understand the impact and consequences of the behavior or the student's ability to control the behavior.

The House bill allows schools to move students whose behavior causes... "significant endangerment to an individual's emotional health or safety that is the result of a physical or verbal assault."

Both bills would also deny protection under IDEA to students who are not yet found eligible for special education and related services, unless the school knew of the student's disability before the situation requiring the disciplinary action occurred. Under either bill, while waiting for evaluation results, the school may change the child's placement.

The House and Senate make different distinctions about the students who may be moved to alternative placements. The House gives schools new authority to move students following "verbal assault" or on assumptions about future behavior. It allows schools to move students whose behavior causes "serious injury" while at school or at a school function and "serious injury" includes "significant endangerment to an individual's emotional health or safety that is the result of a physical or verbal assault." A hearing officer could also order a placement change if the current placement is substantially likely to result in injury to the child or to others. These placements could last up to 45 days.

The Senate bill allows schools to move students with disabilities who engage in behavior that results in serious bodily injury or is substantially likely to result in such injury. Students with disabilities who engage in ongoing "seriously disruptive behavior" that significantly impairs their own or other students' education and their teacher's ability to teach can also be moved to alternative placements. However, schools must first document the behavior and the efforts made to address it before removing such students from their current classrooms. These placements could last up to 35 days.

During passage of the House bill, an attempt was made to modify the original provisions, which were even more punitive. Disability advocates, led by parents, joined representatives of the general education community as the Parent/Educator IDEA Partnership, developed a consensus alternative and presented it to the House committee to moderate certain provisions. More than 30 national education and disability organizations opposed the cessation of education to students with disabilities in the House bill. However, the National School Boards Association and the American Federation of

While more than 30 national education and disability organizations oppose cessation, the National School Boards Association and the American Federation of Teachers believe it is appropriate to deny education services to some students with disabilities.

Teachers believe it is appropriate to deny education services to some students with disabilities. These two groups adamantly support cessation and were successful in keeping these punitive provisions in the House bill.

The Senate bill has not reached the floor yet because the Senate leadership wants to avoid floor amendments. Senator Slade Gorton (R-WA) plans to offer amendments to limit attorney's fees to cases involving "bad faith" by the school and to deny parents of children with disabilities punitive damages under IDEA.

Senator Gorton's amendments are very troubling. Current law allows award of attorney's fees only when the school district is at fault. This encourages parents to sue only when they have a legitimate complaint because they risk having to pay the attorney's fees if the court rejects their claim. Under Gorton's proposal, parents who win in court would be denied attorney's fees even when they demonstrate that the school violated their child's civil rights. The only exception would be if parents can demonstrate that a school acted in "bad faith," which is very hard to prove.

Current law allows courts to determine appropriate remedies, including both compensatory and punitive damages. The threat of punitive damages helps to deter blatant violations of the law. Such awards are now made only for the most extreme school conduct violating constitutionally based rights of students with disabilities.

It is unclear, given the delay in the Senate, whether there will be enough time to pass the Senate bill and then negotiate a final version that can be sent to the President before Congress adjourns in October.

Implications

The outcome of the debate about new disciplinary procedures in IDEA has enormous implications for children with serious emotional disturbance. Important provisions of the current law, developed by Congress and affirmed by the courts, have provided procedural safeguards in response to a long

history of removing students with disabilities from classrooms for inappropriate reasons. These safeguards are under attack.

Although current law provides school personnel with a variety of methods for disciplining students with disabilities, schools will most likely have greater authority to remove children whose behavior is considered problematic. As a result, some students—especially children with serious emotional disturbance—will be punished and excluded when schools fail to create effective educational programs for them.

Mental Health Parity

Health Insurance Reform Act, HR 3103

By a vote of 100-0 on April 23, the Senate approved the Health Insurance Reform Act with language requiring all group, individual and other health insurance plans to provide coverage for mental health services without treatment limits or cost-sharing requirements different from those imposed on other health services. This “parity” amendment was sponsored by Senators Pete Domenici (R-NM) and Paul Wellstone (D-MN).

The original Senate amendment prohibits insurers from limiting coverage because a person needs mental health services. It requires health plans to cover mental health without any arbitrary treatment limits or financial requirements not imposed on coverage of other services. However, it also allows plans to restrict coverage to only medically necessary services by using managed care techniques. The amendment does not mandate a specific mental health benefit and it does not dictate how insurers should achieve parity between mental health and physical health coverage.

The basic purpose of HR 3103 is, first, to make health insurance more portable as people move from job to job and, second, to restrict the use of clauses denying coverage for pre-existing conditions. The House version also included other more controversial amendments, such as medical savings ac-

Nondiscrimination, or parity, for those who need mental health services is an issue that is likely to be considered again next year, both in the context of private insurance and public programs.

counts, which the President has insisted be dropped or he will veto the bill.

Since the Senate vote, the mental health parity amendment has become one of the most talked-about provisions. Caught by surprise, the business community quickly mounted strong, unified opposition to the amendment and used its considerable political power to delete it in conference.

Although there have been no official meetings of the conference committee on this bill, Republican leaders from the House and Senate have been negotiating provisions they would find acceptable in the final bill. These discussions have led to a decision to drop the Domenici-Wellstone parity amendment and replace it with an 18-month study by a politically appointed commission. While inclusion of the study commission keeps the issue alive in HR 3103, there is also the danger that it could delay any future attempts to address parity—and perhaps deter states from acting on such bills—pending the commission's report.

On the other hand, due to controversy between the House and Senate and between Congress and the Administration over medical savings accounts, HR 3103 is currently stalled. As time slips away and the number of legislative days available to move legislation shrinks, prospects for passage of the bill dim. As of late July, it appears highly unlikely that HR 3103 will be enacted. This leaves open the possibility of dealing with parity again next year.

Implications

Enactment of the parity amendment with respect to private insurance coverage would enable children with serious emotional disturbance to access basic mental health services through a parent's coverage. However, benefits under such packages are extremely limited—inpatient hospitalization, outpatient therapy and sometimes partial hospitalization. Private insurance plans do not cover the range of community-based wraparound services these children need to function well. As a result, a parity amendment will not replace federal, state and local programs that address the multiple needs of these chil-

dren. However, the availability of insurance for some services, particularly for more expensive services, could be of benefit by relieving public programs of certain costs.

Congress also considered adding the same language to its Medicaid amendments (see page 12). Under current law, most Medicaid programs provide mental health coverage without arbitrary limits, although they do use preadmission screening and other managed care approaches. On the other hand, under a block grant approach, where mental health services will have to compete for funding with other health care, a Medicaid parity provision takes on far greater significance. The approval of such an amendment by the Senate Finance Committee was therefore very important for children with serious emotional disturbance.

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CONCLUSION

The enactment of any one of the bills making changes to federal entitlements, as described above, would be significant for children with serious emotional disturbance. The *combined* effect of the more drastic proposals favored by the 104th Congress would be truly devastating. Children would lose eligibility for health care coverage and their families would lose critical cash assistance. States would lose significant resources for child mental health services. Mandates would become options, causing advocates for children with serious emotional disturbance to compete head-to-head against other needy populations. Yet the congressional debate over the past eighteen months suggests that policymakers do not understand these children's problems and past experience shows that state policymakers share the same misperceptions.

Examples of the combined impact of some changes illustrate just how bad the situation could become. With respect to eligibility, for example the following proposed changes would combine to drastically reduce the number of children who are entitled to health and mental health care coverage:

- Changes to the SSI definition of childhood disability—even under the more modest proposals now being considered—would cause more than 100,000 children with serious mental impairments to lose Medicaid coverage over the next seven years.
- 2.5 million adolescents could lose Medicaid coverage under the House bill—if only 10% of them require mental health services, this is still 250,000 youngsters.
- States would have the flexibility to define disability for purposes of Medicaid coverage—and many states would be likely to severely curtail coverage of children with mental impairments.
- Significant cuts in federal funding of Medicaid will place pressure on states to reduce their obligations. States are expected to cut back on optional eligibility categories, and to scale back recent expansions of coverage for low-income children even if existing mandates were to still apply. Again, children with serious emotional disturbance would likely be at significant risk.
- School-based Medicaid services are likely to be drastically reduced by Medicaid agencies which face major cuts—recent expansions to school mental health services have often been built on Medicaid funding, but state Medicaid agencies view these as services which should be provided and funded by schools.
- Greater flexibility for schools to reject children with behavioral problems will result in fewer youngsters being eligible under IDEA for special education and related mental health services.
- The child welfare block grant proposed by the House will eliminate automatic eligibility for child welfare services, including family preservation services, for many children.

Examples of the combined impact of some changes illustrate just how bad the situation could become.

Children with serious emotional disturbance have benefited from the inability of the 104th Congress to enact most of its plans. For the time being, these children and their families have avoided serious disruptions in their ability to obtain services.

With respect to service delivery, drastic changes in current requirements and funding levels for mental health services would occur if all of these proposals were enacted at the same time. For instance, funding for community-based wraparound services would be cut as a result of changes to the block grant and reductions in various federal appropriations, Medicaid cuts and the elimination of the EPSDT mandate. Federal demonstration cuts could seriously impair states' ability to develop new initiatives or to network with each other around children's mental health services. Changes to IDEA would reduce the ability of schools to respond to the needs of children with serious emotional disturbance, while Medicaid changes would reduce resources directly available to schools and schools would find community resources for mental health also shrinking. These pressures will make it even more likely that some schools will use the new flexibility around school discipline rules to deny special education and related services to youngsters with serious emotional disturbance.

States would also be operating through a Medicaid block grant which cannot be increased no matter how much the state spends. The tactic used in recent years by state mental health authorities to use their own resources in order to "draw down" federal funds would no longer be applicable. Instead, funding for all mental health services would have to compete at the state level with funding for all other Medicaid health care.

In conclusion, children with serious emotional disturbance have benefited from the inability of the 104th Congress to enact most of its plans. For the time being, these children and their families have avoided serious disruptions in their ability to obtain services.

On the other hand, this fact masks an even more important point—Republicans and Democrats alike have agreed that major cutbacks in federal programs for low-income people are not only acceptable, but necessary. Yet some of these proposed cuts, such as the changes in SSI to eliminate benefits for thousands of children, would have a disproportionate impact on children with serious emotional disturbance. Other cuts that were enacted, including \$13 billion over two years for housing

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programs and \$32 billion from the tax credit for the working poor, will hurt children with serious emotional disturbance. The lowest pending proposal to cut Medicaid is the President's plan to cap the program with a \$52 billion reduction over what would otherwise be spent under current law. Such changes were unthinkable only a few short years ago.

The experience of the debates of the 104th Congress should serve as a serious warning to advocates for these children. Unless policymakers are educated so that they better understand serious emotional disturbance and its impact, these children and their families will again be in the line of fire.

PUBLICATIONS OF INTEREST TO CHILDREN'S ADVOCATES

- In the Line of Fire: Children with Serious Emotional Disturbance and the 104th Congress.* Analysis of changes—actual and proposed—in federally funded programs that provide family support and health, mental health, educational and other services to children and adolescents with serious emotional disturbance. 29 pp. (June 1996) C-7: \$5 (call for discount on 10 or more).
- The Advocate's Guide to SSI for Children.* Manual on financial and disability-based eligibility, application and appeal processes, family reporting requirements, etc. 390 pp. (Jan. 1992; updated Jan. 1995) C-2: \$75 (10% off for payment with order).
- New Guide to the Part H Law and Regulations.* Explains key points of the federally funded infant-toddler

program and the rules for its implementation. Includes list of resource materials. 28 pp. (July 1992) EI-1: \$5 (call for bulk price).

- Making Medicaid Work to Fund Intensive Community Services for Children with Serious Emotional Disturbance.* Discusses states' use of EPSDT and Medicaid's rehabilitation option, targeted case management, waivers and other special approaches, highlighting some of the most successful. 100 pp. (July 1994) C-6: \$9.50
- Coming soon. . . demystifying managed care! Managed Behavioral Health Care for Children and Youth—An Advocate's Guide, and Your Family and Managed Care,* a booklet for parents of children with mental, emotional or behavioral disorders. F-1: \$9.95 for both. Scheduled Sept. 1996

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IN THE LINE OF FIRE was written by Chris Koyanagi and Rhoda Schulzinger at the request of the Child & Adolescent Service System Program Technical Assistance Center at Georgetown University Child Development Center as part of the Bazelon Center's campaign for adequate home- and community-based services and supports for children with serious emotional disturbance.

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